

Responding to the Psychological Crisis of AIDS

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We, the authors, deeply respect the courage of the men who allowed us to publish their most personal thoughts—Mark Bell, Anthony Ferrara, Scott Stamford, Dr. Kim Storch, and others who cannot be named.

AQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) is most frequently understood as a mysterious and deadly medical phenomenon. It strips a person's immune system of the ability to fight off life-threatening infections and cancers. Now there is a growing awareness that AIDS has profound psychological ramifications as well—with a reach far broader than the disease syndrome itself. These mental health aspects of the AIDS crisis begin with the individual person, expand to friends and family, include health care workers who treat people with AIDS, and have begun to engulf whole segments of society.

First, consider one man's experiences:

For the first time in my life, October 1981, I found myself bedridden with a cold that wouldn't go away, viral bronchitis, fever, diarrhea, loss of appetite, and extreme fatigue. These problems persisted for several months and were coupled with the discovery of swollen lymph nodes, which began to really alarm me. Then I developed chronic ear infections, shingles on the backs of both legs, and a persistent sore throat. The diarrhea continued and nausea became a fact of everyday life; eating became increasingly difficult—I began to lose weight.

I was frightened and depressed by the fact that the illnesses were multiple, and that no sooner would one go away than something else would appear. I then began to experience with increasing frequency the most alarming and intimidating of all these maladies—night sweats. Sometimes I would wake up crying because I was so cold and frightened.

No amount of preparation before bed could relieve the anxiety and fear of what was to come. I dreaded what I knew I needed most—sleep; I didn't want to close my eyes.

The initial diagnostic process was probably as confusing and frustrating to the doctors as it was to me. Blood tests and biopsies were always negative or inconclusive; the doctors could only tell me what I didn't have. "Well, it looks like Hodgkin's disease, but it isn't—and it looks like leukemia, but it isn't," etc.

They ruled out the likely and even the unlikely possibilities. I still didn't know. Nothing. I had no idea if it was contagious, if it was curable, if anyone else had it or had ever had it. I was alone, frightened, and confused. I desperately needed help in coping with the emotional turmoil of facing this unknown. Was I going to die?

How should mental health issues related to AIDS be addressed? How can mental health services be integrated into comprehensive health care for people with AIDS? What is the appropriate role for community mental health agencies and alternative self-help approaches? What are the mental health implications of AIDS for lovers, friends, and families of people with AIDS, people with lesser forms of immune suppression, the gay male community in general, and health care providers? We believe that each of these points needs to be discussed.

Since there is little research literature on the psychological aspects of AIDS, we have relied in this paper on our own personal and pro-

fessional experiences. Most important, we have relied on interviews and written statements from several men who have AIDS, from their lovers, and from other family members. Additionally, we have drawn from the experiences of gay community organizations that are struggling to meet the psychological needs of people with AIDS.

People with AIDS

Eighty-five percent of persons with AIDS are diagnosed with either Kaposi's sarcoma (KS), *Pneumocystis carinii* pneumonia (PCP), or both (1). These rare conditions were once virtually unheard of outside of medical circles. Now, however, these diagnoses are well-known and generally thought of as being equivalent to a death sentence. The fact that people diagnosed as suffering from AIDS are likely to have major emotional reactions to hearing the diagnosis should be obvious. Apparently, it is not. We have spoken to several men who have received the diagnosis of AIDS over the telephone from their primary care physicians. No attention was paid to the psychological impact of this diagnosis, and no provisions were made to help the man respond to his emotions.

The director of a mental health crisis center told us that the number of AIDS-related calls has increased geometrically over the past 18 months, including an increasing number of calls about threats of suicide or homicide. These calls are from people who have just been diagnosed with AIDS, or from their family members, who do not know what the future will be or if their

worst fantasies will come true. The director stressed the need, after crisis intervention, to direct callers to sources of support and to continue to follow these people carefully.

We believe that mental health considerations should be part of all assessment and treatment procedures for people with AIDS. At the point of diagnosis, for instance, the practitioner's awareness of emotional factors can help prevent the patient's natural fear and anger from being transformed into self-destructive expressions. During continuing medical treatment, mental health workers can help develop understanding of the emotional needs of both patient and health professional. Psychological assistance during the stages close to death can bring a depth of caring that supersedes the depression and fear at hand.

The role of mental health care practitioners in the AIDS epidemic must encompass an understanding and willingness to deal with factors that make AIDS different from most other disease states—94 percent of persons with AIDS are also characterized by atypical social labels. Approximately 71 percent are gay or bisexual, 17 percent are users of intravenous drugs, and 5 percent are Haitian (2). The fact that most persons with AIDS are culturally different from most physicians and mental health professionals places additional burdens on all concerned.

We pay special attention to the largest group affected by AIDS, gay men. If gay men are to receive optimal health care, their primary care physician must be aware of their sexual orientation. A study by Dardick and Grady indicated that 49 percent of the sample population of lesbians and gay men had told their primary health care professional that they were homosexual, and another 11 percent assumed that their practitioner knew. An additional 34 percent would say that they were lesbian or gay if they thought it was important. Only 7 percent would not share this information under any circumstances. Dardick and Grady found that openness led to greater satisfaction with the primary health care providers and that the attitudes of health professionals

toward homosexuality were an important concern of the respondents (3).

The attitude of mental health professionals toward homosexuality is similarly important. Too frequently, psychotherapy has been characterized by a heterosexual bias, that is, a belief that heterosexual orientation is superior to or more natural (or both) than homosexual orientation (4,5). This heterosexual bias is reflected in diagnostic assessments, treatment goals, and even the language used in psychotherapy (6). The fact that some significant percentage of gay men do not feel emotionally supported by their families and may be isolated from other gay men and women makes it imperative that health care professionals look for, identify, and respond to their special psychological needs (4).

For people with AIDS, psychological needs stem from such psychosocial stressors as fear of death and dying, repeated infections, degenerative physical status, social stigma, fear of exposure of lifestyle, guilt, fear of contagion, loss of lovers or friends, fears of loss of physical attractiveness, loss of occupational and financial status, and increased dependency (7). Given the number and variety of stressors that may be present and the symptoms that may develop (for example, anxiety, depression, and the cognitive deficits secondary to medical treatment), supportive psychotherapy is generally recommended.

In addition to these psychological problems, being treated as a person with a rare disease and being a participant in medical research can be debilitating. One man with AIDS told us:

My treatment with Alpha Interferon required ten daily injections, ten days of rest and ten more daily injections. Within two hours of the first injection, I had severe chills, followed by high fever, and reversion back to chills. These side effects subsided after a few days, but the most devastating were still to come. Over the 30-day course of treatment, I noticed myself becoming profoundly more fatigued and depressed. Where just before the course of Interferon I was still running four miles a day, there were

days now that I barely wanted to get out of bed.

It was at this point that I finally realized what was going to happen to me—I was going to die. From the first moment of that realization to this very day, it is not the act of passing from life to death that frightens me, but the events up to that point. The body and the physical abilities of which I had been so proud, and for which I had worked so hard, are deteriorating with cancer and weakness.

There is virtually nothing I can do or say that will change this situation much. I have been part of four different protocols, or experimental treatments, and have shown improvement on three of them. However, my progress was not sufficient to warrant continuation of any of them.

The Shanti Project

The Shanti Project in San Francisco delivers the types of services most needed by people with AIDS. It is a nonprofit organization that provides free volunteer assistance and counseling on a long-term basis to patients facing life-threatening illnesses. As of September 1983, the Shanti Project had worked individually with 276 persons with AIDS. The volunteer counselors are a heterogeneous group—many coming from the helping professions and almost all having experienced a personal life-threatening illness or profound loss. They are trained, both academically and experientially, to offer a caring presence to the terminally ill patient. Many of the volunteers have themselves been assisted through the Shanti Project.

In addition to counseling, the Shanti Project supplies community volunteers who give not only support and companionship but also such assistance as transportation, cooking, cleaning, and so forth. By being available to take care of mail, plants, or pets and by visiting or taking favorite food, the volunteers and counselors give a sense of continuity to an unpredictable life, and they extinguish many day-to-day worries with which the person with AIDS may be unable to cope.

Support groups are another important, perhaps vital, resource for

people with AIDS offered by the Shanti Project and by similar groups in other cities. Knowing that others face similar problems, fear similar fears, and share similar joys is comforting to each of us—but it is especially necessary for those who are as isolated from society as are many people with AIDS. It is necessary to note, however, that some people with AIDS are unable to face their peers and the reality of their own illness. Watching others whom we learn to care about slowly waste away or suddenly die is extremely traumatic, but the realization for people with AIDS that they are also watching themselves can be too much to handle.

Coordinating Efforts

In San Francisco it is not unusual for people with AIDS to receive services through community health programs or independent providers, as well as assistance from the Shanti Project counselors and community volunteers. However, many volunteer counselors are not trained to handle the complicated problems that arise when suicidal thoughts or severe psychopathology, such as psychotic symptoms, appear. Mental health professionals are needed because they are trained to diagnose and treat the more severe psychological problems that may require medication or hospitalization. Patients need to be referred to community mental health crisis units and to private practice psychiatrists and psychologists. Importantly, these referrals need to be made with care, taking into account the provider's experience with the gay community, understanding of the mental health aspects of AIDS, and receptivity to treating a person with AIDS.

We believe that the needs of people with AIDS cannot be fully met without coordination between community groups and professionals trained in the mental health specialties.

Lovers, Friends, and Family

The mental health aspects of the AIDS crisis affect not only those with AIDS but also the people in their lives. Lovers, friends, and

family are all likely to experience significant distress and may need mental health services. Because AIDS is a mysterious and stigmatized illness, the psychological issues raised for significant others may be more complicated than those for other life-threatening illnesses.

We recently spoke with a man whose lover had died of AIDS only 3 weeks before:

The morning of the day that my lover died, I found him looking into a mirror and crying. That was the first time he had realized just how thin he had become. He went through our house to organize it, to set the hangers in the closet "two fingers apart" as he had been taught in military school, to straighten up our bedroom for review. He told me I should take him to the hospital so that I wouldn't have to deal with his body. Once we were there, I went out to call both of our families. He told me: "Don't worry, I'll wait for you." When I came back, I sat by his bed, we held hands, and he died. I guess he decided that it was better that he died rather than suffer through what he knew he would have to face.

Issues of loss and bereavement need to be addressed most carefully for people with AIDS and for their lovers and family. Since most gay men with AIDS are fairly young (2), their lovers and friends are not as equipped to deal with the issues of death as older people may be. In cities such as New York and San Francisco, where there is a high concentration of AIDS, it is not unusual for someone to have several friends who have been diagnosed (7). The "unfairness" of dying in an epidemic, and of a disease that has no known cure, is exacerbated by the stigma of being gay, living in atypical relationships, and being avoided by many friends out of fear of contagion. The following paragraphs are one man's reaction after his diagnosis of KS:

All of my mental preparation was insufficient to thwart the tidal wave of emotion that swept over me as I received what, at the time, I regarded as a death sentence. I went home that evening in the company

of my lover Michael, feeling the weight of two worlds on my shoulders—mine and his. Wanting to protect him from contracting the disease himself, and from the difficulties that I knew were ahead, I asked him to leave me. He refused.

Michael took the news worse than I, initially. As I look back on those days now, I realize that I didn't have time to think of myself, I was too busy taking care of him. He cried, I guess for about six weeks—to the point that my own emotion had to be contained. Eventually, though, we were able to cry together. It has not been easy allowing myself the relief—the freedom—that such crying brings.

For those of you with friends with AIDS, please remember that this is no time for an "out of sight, out of mind" philosophy. When one of your friends is too ill to participate in your life as they did before, don't just forget them. Remember, this is when they need you the most. If you can, respond to that need.

The lovers of persons with AIDS have special psychological needs. Knowing that one has shared the most intimate contact with another who is dying of a contagious disease can be shattering, and the extent of knowledge about AIDS is such that medical evidence cannot fully dispel these fears. Once more is known about contagion and specific patient characteristics associated with susceptibility, many of these men may feel personally more at ease. Although this group has not been adequately studied, it does not appear that most lovers of people with AIDS have developed the syndrome. Unfortunately, lovers of people with AIDS have more reasons for developing emotional problems than concern over their own health: they are almost certain to face self-righteousness, discrimination, fear, and legal impediments as they help their lover through the last months or years of his life. These are psychological demands that pile atop existing grief and health worries, and they suggest the need for mental health and support services.

When people are diagnosed with AIDS, their friends are faced with a series of distressing issues. Gay

friends may be particularly vulnerable because they can readily identify with their friend. Indeed, friends often over-identify and act as if they have just been diagnosed. Other reactions include awkwardness in discussing the illness and problems in working through their fears regarding contagion. Some people want to be supportive, but may not know how to do so. For many, the diagnosis of a friend leads to existential questions and difficult reappraisals of their own lifestyle. For heterosexual friends who may not have known of the person's sexual orientation, the situation may be similarly awkward (5).

Families of gay men with AIDS have reactions similar to those of close friends. For some, diagnosis brings with it disclosure of a life-threatening illness as well as disclosure of sexual orientation. Families that do not accept the homosexuality of a person going through such a difficult period are likely to experience considerable difficulty. The social stigma of the diagnosis involves a presumption about the person's lifestyle that is a source of stress, and the stigma further complicates the family's bereavement (8).

The Shanti Project reported that as of mid-September of 1983, 632 lovers, friends, or family members of people with AIDS have been given individual counseling. This total is well over twice as many people served as those with AIDS. Thus, each new case of AIDS diagnosed in the country has a ripple effect, increasing the need for mental health services. To our knowledge, no data have yet been gathered about the impact of AIDS on the demand for mental health services in either the public or private sectors, but it is clear that mental health services that are AIDS-related are needed in cities that have a large number of people with AIDS.

The Gray Zone

If AIDS is caused by an infectious agent, it seems reasonable that the agent would produce a spectrum of illnesses ranging from subclinical to fatal. The current definition of AIDS used by the Centers

for Disease Control (CDC) requires the presence of a disease (for example, KS, PCP, or other serious opportunistic infection) at least moderately indicative of defective cell-mediated immunity in a person who has no known cause to account for such a defect (9). A large group of patients can be identified who manifest less well-defined symptoms of immune deficiency. This condition has been variously referred to as pre-AIDS, prodromal AIDS, or lesser AIDS. One man in this group referred to his experience as "life in the gray zone."

Some people report no symptoms but have laboratory evidence of immune deficiency. Some report nonspecific symptoms of fever, weight loss, and chronic lymphadenopathy. Some have such diseases as oral candidiasis and various forms of herpes. One man who has been at the more severe end of this spectrum for almost 2 years reports the following:

I guess I'm luckier than most of the "victims." I've been sick almost 24 months now, and my wife and good friends are still here. I have new friends. My prognosis looks better. Beta-strep was my last infection, but that was over 3 months ago and I haven't been seriously ill since. They now tell me that I definitely do not have CDC-defined AIDS.

I suppose I should feel relieved, yet because of current research findings, I am treated with even greater precautions than ever before. Regardless of what I do have, I'm still in the NIH AIDS Study Group, examined only in "AIDS Precautions" rooms, and now for the first time in 24 months my blood is drawn by a masked, capped, gloved, and gowned mummy.

It is important to note that I no longer have the same sense of fear—I'm not among the 80 percent of AIDS patients who will die. Yet, the emotional trauma and the social judgments were as real as theirs.

No one should have to experience that journey alone, without help.

There is disagreement on how best to meet the mental health needs of this group. Most profes-

sionals believe that supportive psychotherapy—supplying empathy and a nonjudgmental atmosphere in which to discuss any issue—can greatly lower levels of distress. Some researchers and clinicians believe that stress plays an important role in both susceptibility and progression of AIDS, based on findings in psychoimmunology that show a quantifiable relationship between emotional distress and specific immune system functioning (10).

Those suggesting a relationship between stress and immune functioning would argue for active interventions to reduce stress for people with evidence of immune suppression. Biofeedback, relaxation training, hypnosis, or any other techniques designed to teach coping mechanisms for reducing stress could be used. The argument is that some of these people could show increased resistance to illness as a result of practicing stress reduction techniques. This is clearly an area for future research.

The Worried Well

AIDS anxiety has struck gay men across the country, including many without reason to be particularly fearful. These men interpret every cough as PCP, look for KS lesions on their bodies several times a day, and dread minor infections that they are sure will turn into a life-threatening illness. A physician told us:

We are seeing a series of people who, even though they had been tested as much as people test for this, insist on being tested again. No one will give them another screening because they have just had one. They are very anxious and agitated and sometimes depressed, having trouble with work, having trouble with roommates and lovers, all because of this concern. They keep saying: "What's my risk? Do I have it or not? I want another test."

Those who fall into this group are often referred to as the "worried well." These medically asymptomatic gay men have developed psychological symptoms that include actual panic attacks, generalized anxiety, hypochondriasis, and

somatic preoccupation. Often these episodes involve unfounded beliefs that one is actually dying of AIDS. In other cases, episodes involve obsessional thinking about disease. These AIDS-related anxiety states can be sufficiently severe to impair social and occupational functioning.

The worried well can often be assisted by supplying accurate information about AIDS. However, a proportion of this group will require more specific assessment, diagnosis, and treatment. In other cases, stress reduction techniques have proved to be of assistance in treating anxiety symptoms. Many of these people benefit most from traditional psychotherapy that uses uncovering approaches designed to resolve conflicts that have been brought to the surface by the threat of AIDS (11).

The Gay Community

Gay males in general are at high risk for mental health problems because of the AIDS epidemic. The frustrations related to being gay in a nonunderstanding society are magnified by a new and pervasive fear of AIDS. Public attacks against people with AIDS as "immoral homosexuals" who have reaped the rewards for their sins do have an effect on people's minds. Gay males are not unaware that 70 to 75 percent of persons with AIDS are gay males, and this fact gives rise to considerable worry.

As the AIDS crisis worsens, gay men are becoming more concerned. A survey of gay men in San Francisco in March 1983 found that approximately 75 percent of the respondents indicated increased anxiety since they had found out about AIDS. Denial of the problems associated with AIDS was low—only 3 percent agreed with the statement that one need not worry because a cure was forthcoming. Only 8 percent of the respondents felt that they had heard too much about AIDS, and only 7 percent indicated that AIDS had not affected them at all (12).

Gay community organizations in the most heavily affected cities have developed programs to deal with the anxieties that gay men have regarding AIDS. Some of these organizations offer "worried well"

support groups, with the goals of information sharing and support for health-conscious behaviors. AIDS awareness workshops and AIDS phone hotlines are also offered for people to discuss their concerns about AIDS and suggest coping strategies. In addition, many gay organizations have developed and distributed AIDS risk-reduction guidelines. We see an absolute need for cooperation among these gay community agencies and city or county health departments, city or county mental health departments, and providers of mental health services who are in private practice.

The fact that gay organizations are becoming increasingly involved with AIDS as a health and mental health issue illustrates a crucial point. There is real, not just imagined, discrimination against gay people in health care settings and from health care professionals—be it active or passive. Gay men with AIDS have been told that their lovers may not see them in intensive care units—when hospital policy prohibits anyone but "family members" from visiting. Hospital procedures do not allow for a same-sex spouse to take responsibility for an incapacitated patient. Health care workers are often shocked to see two men care for each other so deeply, and it takes time and patience on all sides before the realization dawns that these gay men are no different, yet oddly set apart, from the rest of society.

While it is unrealistic to expect every physician to understand, recognize, and be able to treat all known health problems, it is too often the case that gay-related problems are effectively overlooked or clearly misdiagnosed. Mental health professionals do not necessarily have better or sufficient understanding of the particular issues that lesbians and gay males face. As a consequence, gay-oriented health clinics and social service centers have been formed in those few cities that can support such an operation. These centers serve an important function, but they also lessen the demand on traditional health care professionals to expand their understanding of gay issues.

Although public health agencies have not been outspoken on the topic of assuring appropriate health

care services for gay men, this is changing as a result of AIDS. The editor of *Morbidity and Mortality Weekly Report*, published by the Centers for Disease Control, has written: "The classification of certain groups as being more closely associated with the disease (AIDS) has been misconstrued by some to mean these groups are likely to transmit the disease through non-intimate interactions. This view is not justified by available data. Nonetheless, it has been used unfairly as a basis for social and economic discrimination" (1).

There are psychological ramifications to these stigmas. Someone who is seriously ill is virtually unable to cope with overcoming pervasive homophobia in a hospital staff. Depression over being hospitalized can be counted on to worsen when the person is faced with discriminatory treatment as well. Insensitivity by a few staff members can interfere with extremely positive attitudes of all others.

Clearly, there is a proper role for public health agencies in fighting this discrimination. Staff of health departments and mental health centers can add new, important voices to the outcry. They can sponsor public education programs, work with the gay communities to reduce risk, and intervene with hospitals and professional groups to promote the best possible care for gay men faced with this terrifying epidemic.

Health Professionals

As in any crisis, the AIDS epidemic has brought out many extremely dedicated health care providers. These physicians, nurses, orderlies, psychologists, social workers, and social service workers have spent unprecedented amounts of time helping people in need. But the new "specialists" in AIDS are at risk for emotional distress. Floundering with experimental treatments for an uncertain disease, and losing patient after patient, again and again, is difficult. Being one of the few practitioners in an area who has any understanding of AIDS, and believing that if you do not see this next person perhaps no one else can, leads to personal expect-

tations that are impossible to meet as the AIDS crisis grows. The director of a mental health crisis unit told us:

In the initial phase when I was doing a lot of crisis intervention myself, I would call back the referring person to lament and bemoan what had happened to a 30-year-old man just diagnosed with AIDS. It's about as touching and full of pathos as any situation that I could think of. And then we're called on to go to the next one, to the next one, to the next one . . .

Beyond issues of overwork and burnout, health care professionals are faced with special problems associated with AIDS. Anger is a major part in the lives of most people with AIDS that we know, and this anger is often directed at the practitioner who cannot answer questions, who cannot offer hope, but who counsels participation in yet another experimental procedure for a cure. AIDS is also a political issue; practitioners need to be careful of what they say and how they approach their patients. The specter of political repression for homosexual activity and fears that patient confidentiality will be breached lead patients to demand that their diagnosis not be reported to public health agencies, and this demand brings up ethical problems which must be addressed. The glare of publicity for AIDS-related work can be a burden as well, particularly when requests for media interviews begin to interfere with professional and personal time.

The mental health needs of health care professionals working with AIDS should be a cause for increased concern. Traditional ways of dealing with burnout, such as taking vacations, still work, and these responses need to be relearned. Other techniques may need to be encouraged. The directors of many agencies where there is a high level of stress insist on weekly staff meetings where cases are discussed and, more importantly, individual staff members have an opportunity to discuss personal reactions. Health care providers working with AIDS appear to need either formal or informal ways of talking about their experiences in a

supportive environment. Unless time is set aside to discuss these issues, symptoms of distress are likely to develop rapidly.

The psychological problems facing gay professionals who are dealing with AIDS are immensely complex. Many will over-identify with people with AIDS and push themselves too hard. Certainly, some who are confronted with AIDS patients tend to resurface their own fears of AIDS and may become part of the "worried well." Others have special fears of contagion. The many gay practitioners who are not self-identified are faced with fears of backlash if it comes out that they are homosexual, and the anxiety over possible loss of job and status, merely on the basis of being identified as gay, can be overwhelming. Those who accept being gay, and who work in an environment that is accepting, can build a special network of friends and colleagues who will be supportive. Those who must avoid such public knowledge, for personal or professional reasons, are at high risk for emotional distress unless they have a way to vent and work through their frustrations.

Conclusion

Individuals are reacting to the threat of an unknown but deadly epidemic with fear when strength is needed, with denial when awareness is needed, with guilt when understanding is needed, and with withdrawal when caring is needed. We believe that it is the responsibility of the health and mental health community, as broadly defined, to respond to the psychological needs of persons with AIDS and to the needs of their lovers and families.

Over time, more progress will be made in understanding, treating, and preventing AIDS. If, as it appears, AIDS strikes with varying degrees of severity, many people will undergo the physical and emotional turmoil and live to tell about it. Still others will die, deeply bitter at knowing that the cure will come too late. Many more will be affected by the fear of the disease, and by the suffering of friends, family, or lovers with AIDS. The psychological impact of AIDS is

likely to remain for a long, long time.

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